

FAMILIES OF SMA AT A GLANCE

What is Spinal Muscular Atrophy?

Spinal Muscular Atrophy (SMA) is a motor neuron disease which affects the voluntary muscles that are used for activities such as crawling, walking, head and neck control, and swallowing. **There is currently no treatment or cure for SMA.**

- #1 genetic killer of children under two.
- One in every 6,000 babies is born with SMA.
- 1 in 40 or 7.5 million Americans are carriers.



Families of SMA

Families of SMA is a non-profit organization which has funded and directed over \$50 million for leading SMA research programs. We have 29 Chapters throughout the United States and over 70,000 members and supporters. We also host the world's largest annual SMA Conference with over 1,000 families and researchers from around the globe.

Research

Families of SMA is the leader in SMA research. Our successful results and progress from basic research to drug discovery programs to clinical trials provide real hope for families and patients. Over the last 27 years, FSMA has:

- Discovered a back-up gene, SMN2, for the disease.
- Funded 5 multi-center clinical trials for existing drugs.
- Funded research that led to first ever clinical trial for a new drug designed specifically to treat SMA.

Future goals of our organization include expanding our investment in critical SMA research to grow the drug pipeline and to develop centers of excellence to provide better care management of the disease.

FSMA has funded drug discovery research since 2000. We have been involved in 6 projects with a total investment of over \$18 Million.

Family Support

Our Family Support Department provides crucial services to all families affected by SMA.

FSMA supports families by sending out numerous materials such as:

- Type I, II and III newly diagnosed care packages which provide SMA families with adapted toys, blankets, swings and other items that help stimulate their children.
- Equipment such as bath chairs, car beds, strollers and manual wheelchairs.
- Care services through our Caring Series Booklets and our on-line "Ask the Expert" service.
- Local support through our 29 Chapters nationwide.

Families of SMA now provides services and support to 70% of all newly diagnosed families.

Contact us

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